

A qualitative investigation of parental experience of eating problems in children and young people with Autism Spectrum Disorder and the professional support they have received and desire

Connor, Z, Cooke, S, Hennessy-Priest, K, Kneafsey, R & Lycett, D
Author post-print (accepted) deposited by Coventry University's Repository

Original citation & hyperlink:

Connor, Z, Cooke, S, Hennessy-Priest, K, Kneafsey, R & Lycett, D 2018, A qualitative investigation of parental experience of eating problems in children and young people with Autism Spectrum Disorder and the professional support they have received and desire. in Journal of Human Nutrition & Dietetics. S1 edn, vol. 31, Wiley, pp. 36-37, BDA Research Symposium 2017, Birmingham, United Kingdom, 6/12/17.

<https://dx.doi.org/10.1111/jhn.12536>

DOI 10.1111/jhn.12536

ISSN 0952-3871

ESSN 1365-277X

Publisher: Wiley

This is the peer reviewed version of the following article: Connor, Z, Cooke, S, Hennessy-Priest, K, Kneafsey, R & Lycett, D 2018, A qualitative investigation of parental experience of eating problems in children and young people with Autism Spectrum Disorder and the professional support they have received and desire. in Journal of Human Nutrition & Dietetics. S1 edn, vol. 31, Wiley, pp. 36-37, BDA Research Symposium 2017, Birmingham, United Kingdom, 6/12/17., which has been published in final form at [<https://doi.org/10.1111/jhn.12536>]. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

Copyright © and Moral Rights are retained by the author(s) and/ or other copyright owners. A copy can be downloaded for personal non-commercial research or study, without prior permission or charge. This item cannot be reproduced or quoted extensively from without first obtaining permission in writing from the copyright holder(s). The content must not be changed in any way or sold commercially in any format or medium without the formal permission of the copyright holders.

This document is the author's post-print version, incorporating any revisions agreed during the peer-review process. Some differences between the published version and this version

may remain and you are advised to consult the published version if you wish to cite from it.

Title: A qualitative investigation of parental experience of eating problems in children and young people with Autism Spectrum Disorder and the professional support they have received and desire

Background: Autism spectrum disorder (ASD) is a complex neurodevelopmental condition affecting 1% of children (1). 60-90% of children with ASD experience feeding problems such as extremely fussy eating (2). The setting for this study was a south-east London borough in which parents of children with ASD and feeding problems can access support from various professionals but only a very limited dietetic service is commissioned, and no multi-disciplinary pathway exists. The aim of this study was to examine the experience of parents of children with ASD who have eating problems; any support they have received; and the additional support they would like.

Methods: A pragmatic qualitative research approach with an element of participatory photography was adopted. Ethical approval was granted via the Coventry University Research Ethics Committee. Six participants were recruited using purposive and snowball sampling via NHS dietetic clinic lists, schools, support groups, fliers and social media. All were mothers in their 40s and lived in the south-east London borough. They had seven children with ASD aged six- to thirteen-years-old, two girls and five boys. Data was collected between November 2016 and January 2017 via semi-structured interviews (phone or face-to-face). All participants additionally submitted photographs with captions that illustrated their child's eating problems and the effect on them and their family. Interviews were transcribed and the transcripts, photos and captions organised using the computer package NVivo, and analysed using inductive thematic analysis (3). Rigour was ensured via member checking, peer review of themes and reflexive journaling.

Results: Five themes were identified: 1. Difficult mealtimes (subthemes 1a. unusual eating habits; 1b. trying new food is challenging; 1c. eating problems affect children's health, behaviour, learning and mood; 1d. eating problems impact on parents and families); 2. Unsure when or whether to pursue help; 3. Lowered expectations of parents and professionals; 4. Feeling let down by a lack of support; 5. Services must be easily accessible and supportive (subthemes 5a. the role of school; 5b. a 'super-nanny service'; 5c. group sessions; 5d. online help).

Discussion: This research has provided the first UK exploration of parental experience of feeding problems in children with ASD. Although the sample was small and relatively homogenous, saturation of data was achieved, and the findings echo those from other studies that these problems have a negative impact on the child, parent and family wellbeing (4,5). There were mixed experiences of services, some positive but most negative, feeling let down by the lack of services offered and frequent professional dismissal of feeding problems being normal in ASD and therefore not something to seek help for. Various avenues for improved support were identified including online support and group sessions.

Conclusion: In-depth exploration of the experiences of six parents of children with ASD and feeding problems has been carried out. The study findings will be used to plan multi-disciplinary pathways with the overriding aim of improving the wellbeing of children with ASD their families in south-east London.

References:

1. NICE: National Institute for Health and Care Excellence. Guideline CG128: Autism in under 19s: recognition, referral and diagnosis [Internet]. London, UK: NICE; 2011 [cited 2016 Jul 5]. Available from: <https://www.nice.org.uk/Guidance/CG128>
2. Emond A, Emmett P, Steer C, Golding J. Feeding Symptoms, Dietary Patterns, and Growth in Young Children With Autism Spectrum Disorders. *Pediatrics* [Internet]. 2010 Aug 1;126(2):e337–42. Available from: <http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2009-2391>
3. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* [Internet]. 2006;3(May 2015):77–101. Available from: <http://dx.doi.org/10.1191/1478088706qp0630a>
4. Rogers LG, Magill-Evans J, Rempel GR. Mothers' Challenges in Feeding their Children with Autism Spectrum Disorder-Managing More Than Just Picky Eating. *J Dev Phys Disabil*. 2012;24(1):19–33.
5. Suarez MA, Atchison BJ, Lagerwey M. Phenomenological examination of the mealtime experience for mothers of children with autism and food selectivity. *Am J Occup Ther*. 2014;68(1):102–7.